



Washington State Core Indicators Workgroup Findings

Washington State
Developmental Disabilities Council
July 2005

Introduction

The Developmental Disabilities Council convened a workgroup of self-advocates, family members of persons with developmental disabilities (DD) and community providers to review the results of two Core Indicators surveys conducted in Washington State during 2003-2004. The Core Indicators is a national study that assesses performance and outcome indicators for state developmental disabilities service systems. Washington State Core Indicators survey participants were selected from the caseload of the Division of Developmental Disabilities (DDD).

The workgroup met three times during May and June 2005. The two survey results reviewed by the committee were:

- **Adult Family Survey (AFS)**– A random survey mailed to families with an adult family member with DD living in their family home who received at least one service or support from DDD besides case management.
- **Family Guardian Survey (FGS)** – A random survey mailed to families with an adult family member with DD living outside of the family home or legal guardians. The family member needed to receive service coordination and at least one additional “direct” service or support from DDD to be selected for the survey.

Using the data from the surveys, the workgroup developed systems change recommendations for presentation to the Developmental Disabilities Council and the Division of Developmental Disabilities. The workgroup made recommendations in all five sub-domains of the survey. The five survey areas were:

- Information and planning
- Access to and delivery of services and supports
- Choices and control
- Community connections
- Outcomes and satisfaction with services and supports

In each area, there are recommendations, and a workgroup composite score for each recommendation. Recommendations were ranked (using values identified by the group) on a scale of 1-5, with 5 being a rating of highest importance. Each recommendation includes reference to the supporting data as well as additional input received from workgroup members.

For ease in reading, survey names are abbreviated in the text of the report while detailed information about the surveys, the values used in scoring the recommendations, and the workgroup members are provided in Appendix A.

Information and Planning

We recommend the Division improve accessibility and availability of information about types of services and supports available to families so they can make better informed choices for their family member with developmental disabilities. We recommend that the Division develop informational materials for families and individuals with developmental disabilities that are clear and easy-to-understand. (4.5)

- Only 40.7% of those in the AFS survey reported families in their area always or usually request different types of services and supports be made available in their area. (AFS, Pg. 36)
- When agencies are asked to provide different types of services and supports, only 28.2% of respondents state the state agency always or usually responds to their request. (AFS, Pg. 37)
- Family members stating they seldom or never receive information about the services and supports available to their family member is high (31.6%). (AFS, Pg.21)
- Of those families receiving information, less than half (46.1%) reported the information is always or usually easy to understand. (AFS, Pg. 22)
- Families stating they seldom or never get enough information to participate in planning services for their family member (33.2%) is the highest among the states surveyed. (AFS, Pg. 23)
- The number of respondents in the AFS saying they always or usually get enough information to help participate in planning services for their family member (32.3%) was the lowest of the states surveyed. (AFS, Pg. 23)
- While families feel service have made a difference in helping keep their family member at home (73.2% state differences always or usually made a difference), they are lacking information about what supports are available to them. Only 27.9% responded that they always or usually receive information about the services and supports that are available to them. (AFS, Pg. 66. AFS, Pg. 21)

We recommend improving case management services by decreasing caseloads, increasing the number of full-time case managers, improving case manager training, and providing support specific to caseloads. For case managers serving individuals on the waivers, increase case manager knowledge about systems, services and options for services in the community. (4.25)

- The number of families in the AFS survey reporting their staff member is effective has decreased from 65.3% in 2003 to 53% in 2005. Washington's score was the lowest of the states surveyed. (AFS, Pg. 29)
- In the FGS, the respondent answering the staff who assist them are always or usually effective was near the state average (73.6%), but the number who

stated that the staff are seldom or never effective is the highest of the states surveyed (4.6%). (FGS, Pg. 24)

- 11% of the respondents in the AFS survey responded they never or seldom can contact the staff member they need to assist them whenever they wanted to. This was the highest of the states surveyed. (AFS, Pg. 30)
- 59.4% of those in the AFS survey stated they could contact the staff that assist them with planning whenever they wanted to. This was the lowest score of the states surveyed. (AFS, Pg. 30)
- In the AFS, Washington families reporting that staff who assist them in planning always or usually help them figure out what they need as a family to support their family member is lowest of the states surveyed (43.1%). (AFS, Pg. 26)
- In the AFS, families reporting that staff seldom or never help them figure out what they need as a family to support their family member was highest of the states surveyed (28.7%). (AFS, Pg. 26)
- 93.1% of respondents in the FGS reported that the staff that assist them are generally respectful and courteous. (FGS, Pg. 23)

Access to & Delivery of Services and Supports

We recommend the Division continue to advocate for more medical and dental services, assistive technology/special equipment and other needed accommodations for individuals with developmental disabilities. (4.83)

- Although 87.5% of respondents stated their family member always or usually has access to the special equipment or accommodations, he or she needs, 12.7% stated their family member sometimes, never or seldom has access to the special equipment or accommodations that he/she needs. The seldom or never response is the highest among the states surveyed (4.6%). (FGS, Pg.30)
- High percentages of families indicated that they always or usually have access to medical (86.5%), dental (77.9%) and necessary medications (92.2%) for the family member with a developmental disability. (AFS, Pg. 42-44)
- In the FGS, 81.6% of respondents said services and supports make a positive difference in the life of their family. (FGS, Page 51)
- In the AFS, 64.7% of families felt that services have made a positive difference in the life of their family. (AFS, Pg. 65)

We recommend the Division improve crisis prevention and assure timely response to families and individuals in emergent situations. For case managers serving clients receiving little or no services, we recommend more training in crisis intervention and linking families to specific and generic community resources, including mental health providers and crisis centers in every community. (4.66)

- In the AFS, when families asked for services or supports in an emergency crisis, only 46.3% reported that help always or usually was provided right away. (AFS, Pg. 38)
- Almost one-third of AFS respondents (30.3%) stated they seldom or never were provided help right away when they asked for it in an emergency crisis. (AFS, Pg. 38)

We recommend the Division seek additional funding for the services and supports families need, explore options for blending funding, eliminate waste and mismanagement, improve accountability and advocate for DD services being part of caseload forecasting. (4.66)

- In the AFS, over 53% of families stated they sometimes, seldom or never get the supports they need. (AFS, Pg. 33)
- Percentage of families getting services and supports they need is low. 46.8% of AFS survey respondents stated they always or usually get the services and supports they need. This was the lowest number of the states surveyed. (AFS, Pg. 33)

- 42.4% of respondents stated that the services and supports offered meet their family's needs. This was the lowest number of the states surveyed. (AFS, Pg. 34)
- There is a need to educate the legislature, public employers, case managers, (videos, etc.) about the values, costs, and benefits of providing services for individuals with developmental disabilities.

We recommend that services provided by the Division, contractors and providers be linguistically appropriate and respectful of individual cultures. (4.46 score)

- In the AFS, 42.9% of respondents stated there seldom or never were enough support workers available to communicate with their family member who did not speak English or uses a different way to communicate. This was highest of the states surveyed. (AFS, Pg. 40)

We recommend the Division increase employment supports by coordinating with community agencies and businesses, providing incentives to employers, supporting self-employment, strengthening school to work programs, and educating the public. (4.42 score)

- In the FGS, Washington had the lowest percentage of persons reported receiving day/employment supports (65.7%). (FGS, Pg. 17)
- In the AFS, 52.8% of those surveyed reported receiving day/employment supports. (AFS, Pg. 18)

Choices and Control

We recommend the Division continue to support families' desire for choice and control of services provided for their family member with DD and inform them of service costs. (4.5)

- In the AFS, 48.7% of those surveyed stated they or their family member always or usually decide how money is spent. This was the third highest of the states surveyed. (AFS, pg. 55)
- Number of families always or usually knowing how much money is spent by the MR/DD agency on behalf of their family member with a developmental disability is 25.8%. This is over twice the number reported for the same question in 2003 (AFS, Pg. 54)
- 68.3% of WA families in the AFS responded that staff that assist them with planning, respect their choices and opinions. This was the lowest of the states surveyed. (AFS, Pg. 27)

We recommend increasing choices for families and individuals with developmental disabilities in selecting support staff by educating individuals and families about their right to a choice in support staff and encouraging firms that hire support workers to include individuals with DD and their families in the hiring process. (4.33)

- A little more than one third of families (35.9%) in the AFS survey report they are always or usually choose the support workers who work with their family. (AFS, Pg. 50)
- In the AFS, the number of families wanting to have control or input over the hiring and management of their support workers was the highest of the states surveyed (66.8%). (AFS, Pg. 53)
- In the FGS, 13.7% of respondents stated that they always or usually have control or input over the hiring and management of support workers. This is the highest of the states surveyed. (FGS, Pg. 38)
- In the FGS, 29.7% of respondent stated they or their family member want to have control/and or input over the hiring and management of their support workers. (FGS, Pg. 39)
- Frequent changes in support staff is always, usually or sometimes a problem for 57.9% of families responding in the AFS survey. (AFS, Pg. 45)
- Frequent changes in support staff are a problem for all states surveyed. (AFS, Pg. 45)
- In the AFS, 92.5% of those surveyed reported support staff are always or usually respectful and courteous. (AFS, Pg. 47)

Community Connections

We recommend the Division increase community inclusion by collaborating with other systems and community organizations and exploring ways to facilitate individuals' and families' involvement in the community. (4.58)

- In the AFS, the number of people stating staff seldom or never help them connect to typical community supports is the highest of the states surveyed (52.6%). (AFS, Pg. 57)
- The number of respondents stating that the staff that help them plan help connect them to community supports has decreased from 31.9% in 2003 to 24.4% in 2005. (AFS, Pg. 58)
- People living out of home had higher reporting of community connections (39.1%) than those living in their family home (27.9%). (FGS, Pg. 46. AFS, Pg. 60)
- In the AFS, over one-third of the families (37.2%) reported their family member seldom or never participated in community activities. (AFS, Pg. 60)

Outcomes & Satisfaction with Services & Supports

We recommend the Division continue to survey and seek input from their customers to improve service quality, including in-person interviews by independent parties. (4.66)

- DDD should continue to take part in the National Core Indicators to measure the satisfaction of individuals with developmental disabilities and their families with the services and supports it provides.
- DDD should look at similar states to Washington that have scored higher than Washington to identify any strategies that can be transferred to Washington's service systems.

We recommend the Division's Grievance Procedure be clearly explained to both people with developmental disabilities and their family members at least annually. We recommend the grievance policy be written and presented to families and adults with DD in an easy-to-understand format, with use of graphics and charts, and that adequate time is allowed to cover both the procedure and any questions or follow-up concerns. (4.33)

- The number of respondents indicating they were familiar with the procedures for filing a grievance was low in both studies. Only 34.1% of those in the AFS stated they were familiar with the grievance procedure, this is down from 36.7% in 2003. (AFS, Pg. 63)
- Only 42.6% in the FGS were familiar with the grievance procedures, up only slightly from the 42.3% reported in 2003. (FGS, Pg. 49)
- The number of families in the AFS stating they don't know the grievance procedure was the highest of the states surveyed (55.3%). (AFS, Pg. 63)

General Comments

1. Overall, Washington is falling further behind on many or most measures.

- In the AFS, Washington's 2005 scores dropped for 18 of the 34 questions. Compared to other states, Washington's 2005 scores were lower or much lower than the national average in 23 of the 44 questions and higher or much higher than the national average for only 5 of the 44 questions.
- In the FGS, Washington's 2005 scores dropped for 6 of the survey questions. Compared to other states, Washington's scores were lower or much lower for five questions and similar to other states for the remaining 24.

2. Information is not getting to families. There is a need for one central "home" for communication. Need to look at methods of communication and determine whether they're working.

3. Need to support true inclusion and a stronger voice for self-advocates and their families, and identify what are the barriers that keep people from participating in the community.

4. In the Family Guardian Survey (where individuals are residing out of their family homes) scores are higher when compared to the Adult Family Survey responses (where the individuals reside in their family home).

- In out of home placement, people have more people involved in their lives, increased access to information, and more participation in planning services. More people involved with adults with developmental disabilities seems to equal better quality of care.

Appendix A: Reviewed Material & Panel Composition

In developing their recommendations, the panel reviewed the data collected through surveys done in Washington State under the National Core Indicator's Project. More detailed information can be found on each survey on the Internet:

Adult Family Survey:

http://www.hsri.org/docs/786_P6_AFS2004_Final.pdf

Family Guardian Survey:

http://www.hsri.org/docs/786_P6_FGS2004_Final.pdf

Previous Core Indicator Workgroup reports are available at the DDC website, on our publications page.

The address is: <http://www.ddc.wa.gov/Publications.htm>

States/Counties Participating in the Adult Family Survey

Arizona	Oklahoma
California - Orange County	Pennsylvania
Connecticut	South Carolina
Maine	Washington
North Carolina	West Virginia
North Dakota	Wyoming

States/Counties Participating in the Family Guardian Survey

Arizona	North Dakota
California - Orange County	Pennsylvania
Connecticut	South Carolina
Maine	Washington
North Carolina	Wyoming

Values Used in Scoring Recommendations

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| ▪ Choices | ▪ Common sense |
| ▪ Respect | ▪ Inclusion |
| ▪ Honesty | ▪ Community |
| ▪ Participation | ▪ Opportunities |
| ▪ Teamwork | ▪ Independence |
| ▪ Self-determination | ▪ Equity |
| ▪ Knowledge | ▪ Justice |
| ▪ Relationships | ▪ Advocacy |
| ▪ Pride | ▪ Diversity |
| ▪ Every voice counts | ▪ “Person” first |
| ▪ Freedom | ▪ Safety |
| ▪ Family | ▪ Friendship |
| ▪ Integrity | ▪ Flexible |
| ▪ Competence | ▪ Trust |
| ▪ Power | ▪ Influence |
| ▪ Sensitivity | ▪ Dedication |
| ▪ Education | ▪ Access |
| ▪ Equality | ▪ Commitment |
| ▪ Experience | ▪ Home |
| ▪ Clear communication | ▪ Personal ownership |

Workgroup Members

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